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# Altered sensory perception among people living with cancer

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## Summary

This qualitative study is based on evidence that people living with cancer may suffer from temporary or permanent impairment of their perception of smell, taste and texture. The objective of this study is to examine the personal and social effects of these changes from the viewpoint of culinary discourse research. To this end, the study consisted of structured interviews with people living with cancer and their relatives. The transcripts were evaluated in accordance with MAYRING'S qualitative content analysis. It turned out that the processes through which people with disease-related changes to their perception and sensory systems returned to their socio-cultural backgrounds were influenced by their respective culinary biographies and the effects of nutritional education. These significantly determined the coping strategies and patterns of those concerned. In their efforts to restore their individual (and also partnership-based) *culinary sense of coherence*, those affected generally discovered that the flavor of food is more just than gustatory perception.

**Keywords:** cancer, culinary discourse, sensory perception, sense of coherence, eating habits

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## Introduction

### Impairment of sensory systems by cancer

Cancers, as well as cancer therapy and aftercare, can cause both temporary and permanent disturbances to the sense of smell and taste [1–3]. These impairments in sensory perception range from the complete loss of taste and smell to permanent alterations. Changes may affect the taste of saltiness, sourness, sweetness or bitterness, may result in a metallic aftertaste or be combined with a general decrease in taste ability [1, 4]. Taste preferences may also shift. Specific causes for changes in taste and smell have still not been clearly determined [3]. Those affected lament the reduced joy in eating and drinking and the consumption of food in general [3, 4]. These changes may have a considerable impact on everyday life and may often prove to be a heavy burden for those affected as well as for relatives [3, 5, 6]. Of the 340 patients surveyed by BERNHARDSON et al. [5] who had experienced changes in taste and smell, half felt very stressed and a third felt very despondent as well as considerably restricted in the management of everyday life.[1] Malnutrition, weight loss and nutritional deficiencies may arise as a consequence [7–9]. Nevertheless, there is a lack of *"[e]videnzbasiertes Wissen für Ernährungsberater und andere Gesundheitsexperten bezüglich der Ernährungsberatung für Patienten mit Geschmacks- und Geruchsveränderungen"* (evidence-based knowledge for nutritionists and other health experts on nutritional counselling for patients with changes in taste and smell) [10].

This study focuses on how oncology patients cope with everyday life. Those interviewed as part of this study spoke about how they handled impairments to their perception of smell, taste and texture in everyday life. This study provides the first findings for nutritionists and health experts on patients returning to their habitual eating community.

### Nutrition, eating behaviour and culinary discourse

In addition to the fact that people must eat to survive, food (as a fundamental need and a pleasure need) shapes the communicative complexity of life to the extent that we can today extrapolate Marcel MAUSS' understanding of eating and drinking as a "total social

[1] High distress/high impact on daily life (HDHI)

fact" (1923) [11]. In order to understand the reasons and motives for personal and collective eating behaviors, we can broaden the scientific/biomedical meaning of nutrition to include an understanding of how people's personal attitudes and patterns of interpretation determine the actions of food selection and eating. Almost counter to nutritional science, the individual appears to search for eating experiences whose sensory diversity he/she recognizes or craves. In this context, the notion of the sensory always includes the emotions experienced through food and the atmosphere experienced when eating. Eating and drinking never amount solely to the mere satisfaction of feelings of hunger or compliance with nutritional recommendations [12, 13]. The individual acts on these experiences of taste variety which almost always lie in the past, relate to other people and encompass certain eating situations. And this is precisely where stories emerge as a genus of culinary discourse, filed as a memory, later retold and embroidered, and adapted to the respective social context of occasion and exchange.

The understanding of the culinary belongs to the specialist concept of culinary studies and is derived from lat. *culina* (kitchen) und lat. *culinaria* (what belongs to the kitchen). Kitchens play a central role in the preparation of food and the related practical communication in people's living environment; they are an essential component of everyday eating culture [11].

As a result of the genus of culinary discourse, the authors introduced the notion of culinary sense of coherence, based on Aron Antonovsky's sense of coherence (SOC) (1997) [14], which describes the successful management of everyday life. In this research project, this relates to the management of disease-related disturbances in everyday interaction with eating and nutrition, through comprehensibility, operability and feasibility. This study may be used for clinical practice and nutrition counselling purposes to show which strategies people living with cancer draw on in order to restore culinary coherence. The study results may be consulted for the conception and development of (outpatient) interventions which focus on coping with everyday life after cancer therapy.

## Represented realities

In research, **mimesis** designates the represented reality. The authors have utilized this concept, as the narrator is his/her own author. In narrative research, how things actually occurred at the time of the experience are not relevant, instead it is the meaning the narrator has given these experiences through the filters of choice, emphasis and formulation.

## Question and methodology

The objective of this study is to examine the individual and social effects of these changes from the viewpoint and logic of culinary discourse research. The researchers' approach was guided by questions on how people with cancer-related changes in perception and sensory systems as a result of cancers operated in culinary discourse and how they shaped and changed this.

Eight structured interviews were carried out with people living with cancer. Of these, four were suffering from cancer at the time of the interview, two identified themselves as free of cancer and two were relatives. The participants exhibited heterogeneity in gender, age, marital status, level of education and type of cancer. They were equally male and female and aged between 42 and 80. The dates of the initial diagnoses were between 1.5 and 15 years prior to the time of interview. The interviewees were drawn from participants in a self-help group run by the *Krebsgesellschaft* (Cancer Society) of Schleswig-Holstein. This study focused on the analysis of realities represented by those affected, who were experiencing or had experienced cancer-related changes in perception and sensory systems. The transcripts were evaluated in accordance with Mayring's qualitative content analysis [15]. In order to be able to illustrate the physical changes associated with the progression of a cancer, the social effects and the processes of coping with changed perceptions, the interview questions were phrased in such a way that participants were repeatedly given space to speak freely (episodically) [16]. These narrative sections ensured the necessary degree of openness, so that the interviewees were able to broach what they saw as the important themes related to their personal disturbances in perception of smell, taste and texture. The interview guidelines included questions on general eating behavior, sensory systems, the cancer and its therapy, and the associated changes. Due to the complexity of the micro-stories and the lack of preliminary studies, a combination of deductive and inductive methods was used to create categories for the evaluation of transcripts [15]. Theoretical correlations were generated from these categories. The represented micro-stories revealed central and recurring patterns which gave important indications and directions, which guided and structured evaluation and analysis. Five main categories were derived from the results.

## Results[2]

### Cancer is life-determining

The interviews point to the particularly heavy burden experienced as a result of the medical treatment associated with cancer and its consequences, so changes in sensory perception initially appear to fade into the background. *"You have so many things, you have to straighten it out with your family, you have to inform everyone around you (...) or not. [...] You have so many things that you are thinking about, so you don't even conceive the IDEA, (..) that you cannot taste anything."* (Original citation: *"Man hat so viele Sachen, Sie müssen es mit Ihrer Familie abklären, Sie müssen Ihrem Umfeld (...) Bescheid sagen oder auch nicht. […] Sie haben so viele Sachen, die Sie bedenken, da/ Sie kommen gar nicht auf die IDEE, (..) dass Sie nichts schmecken könnten."*) (W4 162)

Those affected and their relatives associated the cancer treatment with severe physical symptoms and limitations: *"//That// NAUSEA. [...] I sometimes thought I was turning/ pulling myself to the left [...] THAT is when I learnt to pray."* (Original citation: *"//Diese// ÜBELKEIT. […] ich habe manchmal das Gefühl gehabt, ich drehe mich/ ziehe mich auf links […] DA habe ich Beten gelernt."*) (W2 351–355)

Side effects of chemotherapy, radiotherapy and operations affecting the masticatory system, oral cavity and oral flora, also take away the desire to consume food. In addition to the potentially permanent impairments to sensory systems, the interview participants also felt heavily restricted by the physical changes, whether visible or invisible. Here the interviewees frequently criticized the insufficient information they had received about risks, side effects and the cancer therapy itself.

### Culinary biographies and nutritional education

The strategies for coping with changes in sensory systems appear to be dependent on the culinary biographies of those affected. Learnt behavioral patterns formed the basis of how impairments were faced:
*"My mother always cooked well, [...]. And I've always had a habit [...] I'm an old "pot watcher", [...] That was already there, it stuck with me somehow, I don't know. [...] I had// somewhere a, I used to enjoy eating béchamel potatoes with/[...] with strips of pork sausage in. And my wife made that for me [...] I tried to eat it [...] but couldn't taste anything. (.) Ah, I've also not eaten it since, but other things. Ah that means, ah sometime I will eat it again, but ah, but that was a long time ago. But that didn't dishearten me, instead it encouraged me and I said: perhaps it will come back, if it doesn't come back, I'll taste other things. So I even try that."* (Original citation: *"Meine Mutter hat immer gut gekocht,[…]. Und ich habe, äh schon immer eine Angewohnheit […] ich bin ein alter Topf-Gucker, […] Das war damals schon, es steckt irgendwie drin bei mir, ich weiß es nicht. […] ich hatte// mal irgendwie ein, ich habe früher gerne gegessen Béchamelkartoffeln mit/ […] mit, äh Fleischwurststreifen so drin. Und das hat mir meine Frau gemacht […] das habe ich probiert zu essen […] schmeckte überhaupt nicht. (.) Äh, ich habe es seitdem auch nicht wieder gegessen, aber andere Sachen. Äh das heißt, äh irgendwann werde ich es auch mal wieder essen, aber äh, ist aber schon länger her, dass das war. Aber das hat mich nicht entmutigt, sondern ermutigt und da habe ich gesagt: Vielleicht kommt es wieder, wenn es nicht wiederkommt, schmecken mir andere Sachen. Da probiere ich eben das."*) (M4 98–106 u 405–411)

Those affected by cancer exhibited different basic culinary skills and interests. Knowledge and abilities could have been acquired as part of an occupation, by cooking at home or due to an interest in food and others' cooking.
The smell of certain foods is linked to biography; smells trigger feelings, (taste) memories and expectations.
*"So it is always like this, when [...] the cozy time starts with hearty things, when you make cabbage rolls, you come home and smell the cabbage. That has something cozy, something homely and (breathes out) and then when it also tastes good, then everything works out."* (Original citation: *"Also das ist immer so dieses, wenn […] die gemütliche Zeit anfängt mit den deftigen Sachen, wenn man Kohlrouladen macht, man kommt dann nach Hause und man riecht diesen Kohl. Das hat was Gemütliches, was Heimisches und, (atmet aus) und wenn die dann auch noch gut schmecken, dann ist alles gelaufen."*) (W1 229)

### Returning to everyday eating community

Varying degrees of sensory changes appeared amongst all the participants affected by cancer as a side effect of cancer therapy. These changes arose above all in connection with chemotherapy and radiotherapy:
*"Chemo made everything taste like iron, everything was metallic."* (Original citation: *"Die Chemo hat alles äh nach Eisen schmecken lassen, es war alles metallisch."*) (W4 110)

None of those interviewed who had lived or were living with cancer reported that they encountered these taste impairments in hospitals. As patients they generally received one type of food after therapy, usually of the type more associated with baby food (some sort of mashed food):
*"My wife, I have to say, was really messed up by her operation in the hospital*

[2] In these interview transcripts, curved brackets refer to a pause by the interviewee, full stops indicate the length of the pause. Square brackets represent omissions made by the authors.

*with the meal, she always had to eat meal, oatmeal and oat gruel."* (Original citation: *"Meine Frau, muss ich sagen, ist mal versaut worden, durch ihre Operation im Krankenhaus mit ihrer, mit ihrem Grieß, musste sie immer Grieß und Hafergries und Haferschleim essen."*) (M1 200)

Separation from everyday eating habits at the domestic table often arises as a result of recurring stays in hospitals and rehabilitation clinics. The person affected returns to the habitual social environment during or after cancer therapy. The first encounters with habitual and even favorite foods are experienced as very drastic by those affected and their caregivers. Those affected sometimes experienced great disappointment when first tasting their favorite foods, which they had looked forward to eating.
*"And then I got ready for a real fruit dish. [...] And then I sat down (.) and began to eat and THEN I realized that everything tasted the same. [...] I cried my eyes out."* (Original citation: *"Und dann habe ich mir eine richtige Obstschale im Dings fertigmachen lassen. […] Und dann habe ich mich hingesetzt (.) und bin dann angefangen zu Essen und DA habe ich festgestellt, dass alles gleich schmeckte. […] Ich habe Rotz und Wasser geheult."*) (W2 325–327)

This return to the culinary discourse with altered sensory perceptions can also prove to be a great challenge for relatives. They often cooked favorite foods, which the person affected could no longer enjoy. The culinary discourse determined within the partner relationship had disappeared:
*"But you do it anyway, you try it again and again, because somewhere you try?/or believe that perhaps it will work, perhaps it will taste."* (Original citation: *"Aber man macht es trotzdem, man versucht es auch immer wieder, weil man irgendwo immer wieder versu?/ oder glaubt, vielleicht klappt es ja mal, vielleicht schmeckt er es ja mal."*) (W1 394)

## Coping strategies

### *Valuation-driven coping strategies*

After they return to the habitual eating community, those living with cancer attempt to recover culinary coherence. For this purpose, sensory changes were e.g. positively reinterpreted and thus associated with another valuation.
*"[…] [T]he sense of smell grows, I mean. But that might also only be a feeling (...) actually I, beforehand you don't consider anything like that and now I concentrate on the things I still have."* (Original citation: *"[…] [D]er Geruchssinn steigert sich, meine ich. Das kann aber auch nur ein Empfinden sein, weil, äh (.:.) ich wesentlich, früher hat man auf so was nicht geachtet und heute konzentriere ich mich auf die Sachen, die ich noch habe."*) (M4 269)

When changes arose in the sense of taste, and food elements could no longer be tasted, the smell of food acquired greater importance in food interaction for most of the participants affected by cancer. Changes in taste or the loss of taste can also e.g. be placed in the context of efforts to lose weight and be valued positively ahead of this health factor.
*"You don't eat so much anymore. (..) because it doesn't TASTE of anything. (.) I now eat only until I'm full, (.) whereas otherwise you would, if it's tasty, perhaps take a second helping [...] my friend so often says: Now TAKE more. Or can you not TASTE it? No, I say: (.) I'm FULL. [...] For you get tempted, if you sit at the table together and the other is behind (.) and it's TASTY and it TASTES, to take some more. (.) No [...] not for nothing was I so fat."* (Original citation: *"Dadurch isst man nicht mehr so viel. (..) Weil der GENUSS ja nicht da ist. (.) Ich esse jetzt nur bis ich satt bin, (.) aber sonst würde man ja, wenn man/ das lecker ist, ja vielleicht dann noch mal Nachschlag nehmen […] mein Bekannter sagt ja so oft: Nun NIMM doch noch mal. Oder SCHMECKT es dir nicht? Nee, ich sage: (.) Ich bin SATT. […] Denn man kommt ja leicht in die Versuchung, wenn man (unv.) zu zweit am Tisch sitzt und der andere langt nach (.) und es ist LECKER und es SCHMECKT, dass man noch mal was mitnimmt. (.) Nee […] ich war ja nicht umsonst so dick."* (W2 515–527)

### *Emotion-driven coping strategies*

Emotion-driven strategies were also implemented by some participants through setting and tracking food-related targets.
*"I still have one target, that's fish sandwiches, I'll get there too. [...] And I'm working on it."* (Original citation: *"Ich habe noch ein Ziel jetzt, das ist Fischbrötchen, da komme ich auch hin. […] Und, äh ich arbeite dran."*) (M4 134–144)

The temporary destruction (e.g. for rehabilitation measures) of relationships and therefore also of the private culinary discourse can be regarded as an emotion-based coping strategy. Those affected can thus experiment with food away from the rules of the habitual eating community and tastes of the respective relationships. The enjoyment of sugary or fatty foods is also linked to emotions for many people. Even with changes in sensory perception, these luxury foods continue to play a major role in the life of those affected, and they still consume such foods, even if they are thereby ignoring nutritional recommendations for cancer sufferers.
*"[…] I still eat sweet things, even though it is like poison for a cancer sufferer, I don't even taste them, but (laughs) I need them. Whatever."* (Original citation: *"[…] [I]ch esse, obwohl es Gift eigentlich ja ist für einen Krebskranken, nach wie vor süße Sachen, die ich zwar nicht schmecke, aber (lachend) ich brauche sie. Wie auch immer."*) (M3 64)

### *Problem-driven coping strategies*

Participants had primarily developed problem-driven coping strategies. They tended to tackle impairments in sensory perception when eating by developing (alternative) strategies, planning meals, seeking instrumental support and other types of active management. In the case of changes in

taste, participants avoided or reduced spices, or replaced them with others. Sweeteners (e.g. stevioside) were also used when the sweet taste was impaired. If the person affected had not already assumed food preparation duties within the partnership before the illness, that person subsequently took on these tasks. In the case of pain arising in relation to food consumption, those living with cancer helped themselves by taking medication or by learning suggestive coping approaches such as e.g. hypnosis.

### Taste is more than tasting

The sensory perception of all participants (formerly) suffering from cancer changed either in the short term or permanently after cancer therapy and treatment. This influenced their relationship with food and their habitual eating situations. Those living with cancer who experienced lasting impairments in sensory perception thereafter focused on the variety of possible sensory factors involved in food preparation and eating situations and attributed an important role to these. Senses other than taste became more important (e.g. sight, i.e. looking at food) and allowed those affected to make contact with food in a different way. The olfactory sense and the idea of the taste of food were particularly essential in the restoration of culinary coherence.

*"Smelling [...] in food preparation. Or also, in checking whether it is still ok. Ah, it added little, (.) the eye (..), I want, I also try to dress it a little, so that it looks good."* (Original citation: *"Riechen […] [b]ei der Zubereitung. Oder auch, im Überprüfen, ob das noch in Ordnung ist. Äh es kommt wenig dazu, (.) das Auge (..) ich will, versuche das auch ein bisschen anzurichten, dass es schön aussieht."*) (M4 212–213)

The biographically learnt taste experience also became part of the pleasure experience; the sense-sensory becomes secondary to the virtual-sensory taste experience.

*"I sometimes close my eyes (.) and then I can really imagine what I'm eating. (..) And then I eat with an appetite."* (Original citation: *"Ich mache manchmal die Augen zu (.) und da kann ich mir richtig vorstellen, was ich esse. (..) Und esse das dann auch mit Appetit."*) (W2 213)

Learnt mood-dependent eating experiences – the emotions of certain foods – can remain extremely important in spite of impairments in sensory perception.

The purchase and selection of foods can also be full of meaning as part of the sense-associated taste experience. The atmosphere of (shared) cooking and eating as a sensory element of taste variety again emerges as a central category in the micro-stories.

*"Since he's been home, we've cooked together, (.) naturally that is always very nice and I find that too, so it's a lot of fun."* (Original citation: *"Ähm seitdem er zu Hause ist, wird auch gemeinschaftlich gekocht, (.) das ist natürlich auch immer sehr schön und das finde ich eigentlich auch, also es bringt sehr viel Spaß."*) (W1 147)

The taste experience becomes secondary to the socio-cultural significance as the *sense of taste of community*. (Shared) cooking and eating experiences appeared to be an integral part of taste variety among those affected by cancer.

## Discussion

The study results show that the depressive moods experienced by cancer patients are primarily due to the experience of cancer as a whole and the associated problems [1]. The changes which arise in relation to eating and the associated culinary and social complications are first perceived in the private sphere and when returning to the *everyday eating community*. Those affected criticized what they felt was unsatisfactory information on the possible physical, psychological and social side effects and delayed effects of cancer treatment and therapy they experienced. This also tallies with results in existing research [4].

During cancer therapy the person affected abandons his/her habitual environment and as a patient enters the logic of health facilities. Patients and relatives are not prepared for the return to habitual eating habits in the domestic community. The culinary world of those affected by cancer is altered. Familiar foods no longer taste or actually cause pain.

Eating communities have their tastes, rules, rituals and patterns of food selection. The sensory-restricted member of this community faces the challenge of returning. Flexibility in preparation methods, culinary spaces and quality of sense of taste and thus adaptability to impairments in sensory perception and achievements in coping with such depend on the respective culinary biography and nutritional education.

Those affected develop valuation-, problem- and emotion-driven strategies to recover culinary coherence. Those affected by cancer concentrate on the remaining senses, positively reinterpret losses or take over responsibility for food preparation. They establish and work towards food-related objectives. Eating communities are also temporarily abandoned in order to be able to shape a relationship with food individually. In food preparation and eating situations the participants affected by cancer concentrate not just on the taste, but also on the smell, appearance and perceived quality of food used or the arrangement of food. A particularly important role is given to the olfactory and virtual-sensory taste of meals; the biographical and *communal sense of taste* of meals also increases in importance.

Medical information is a first and important step in the process of returning to everyday eating habits. At this point much importance may be ascribed to the first meals

experienced after treatment and to nutrition counselling and education as part of rehabilitation measures. There should be opportunities to experiment with food, to recognize the extent of individual limitations and alternatives at an early stage. Patients must be prepared for the return to everyday culinary discourse. Those affected need counselling and information beyond the clinical context e.g. from professional associations.

### Limitations

Qualitative social research studies social correlations whereby verbally-communicated experiences of individual people are placed at the center of the study. In this instance we do not claim to establish generally valid laws. The limitations of this study arise from the small number of interviews, the heterogeneity of the cancer sufferers and the (occasionally) long periods of time since the initial diagnosis. Previous studies also show that impairments caused by disturbances to the taste and smell of those affected by cancer are evaluated very differently by individuals [17]. It has also been shown previously that patients find it difficult to distinguish between smell and taste [18].

## Conclusion

There is a general lack of oncological research in the area of psycho-social effects of changes in sensory perception. Disturbances in the perception of smell, taste and texture may no longer be considered irrelevant [17]. This study has taken the first steps; additional studies are required to make further recommendations for clinical contexts and (nutrition) counselling and to develop interventions as part of cancer therapy. This study has shown that the return to everyday eating habits must begin in the preliminary discussions before cancer therapy.

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**Conflict of Interest**
The authors declare no conflict of interest.

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